JOINT MPH PROGRAM
UNIVERSITY OF GONDAR AND ADDIS CONTINENTAL INSTITUTE OF PUBLIC HEALTH

ASSESSMENT OF THE MOTIVATION AND CHALLENGES OF VOLUNTEER HOME BASED CARE-GIVERS OF PLWHA IN ADDIS ABABA.

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A THESIS SUBMITTED TO THE SCHOOL OF PUBLIC HEALTH, UNIVERSITY OF GONDAR, IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTERS IN PUBLIC HEALTH

JUNE 2009
ADDIS ABABA, ETHIOPIA

Abstract

Background: Although HBC programs are believed to have multiple benefits for the health system, the patients and the community, its dependence on volunteers who are mostly poor made its sustainability questionable. The sustainability of HBC program largely influenced by volunteers' motivation and the challenges they face.

Objective: To assess the motivation and challenges of volunteer home based care-givers of PLWHA in Addis Ababa.

Methods: A qualitative study was conducted among volunteer home based care providers for PLWHA in Addis Ababa. The study was conducted from April - May 30, 2009. The data was collected using in-depth interviews and focus group discussions. The data were analyzed using a modified Grounded Theory.

Result: Motivation to providing HBC evolve in to three stages; the entry, continuation (sustaining), and quitting (ending). Motivation at entry is largely due to loss of beloved ones and unemployment. The continuity depend on the 'hope' of better job opportunity and material and financial support and ending happens when better job is secured or support is withdrawn.

Conclusion and recommendation: Poverty/unemployment is the most important factor during volunteerism. Volunteers can maintain their commitment if they are provided sufficient support or when they see a better hope for rewarding job as a result. Therefore, HBC organizers must pay attention to the needs of volunteers to ensure sustainability of the program.

Key words: Motivation, Challenges, poverty, Qualitative study, In-depth interviews, Focus group discussions, modified Grounded Theory, Open code.

1. Introduction

Ethiopia is one of the highly HIV/AIDS affected countries of the world. The scale of the epidemic calls for increased efforts to ensure care services. However, even in the places where there is optimal health service system, health services alone would not be able to cope with the high demand for care services (1). The gap can only be filled by making care and support available at community and home level (2). The large number of HIV infections (an estimated 3 million), poor health service coverage, and hospital bed occupancy rate of 50 percent and above with AIDS patients made home-based care a substantial reinforcement for adequate patient care and support in Ethiopia (3). Ethiopia adopted home-based care as an AIDS response strategy and issued national guide lines in 1996 and 2001.At that time, families provided most of the care and support. Yet the quality of care was uneven and sometimes nonexistence (4).

In the mid to late 1990s, upon realizing that the public sectors of most poor, highly affected countries were ill equipped to handle AIDS-related morbidity, programmers and policy-makers considered ways to shift the clinical care from the formal health services to the Community. According to (5) many of these programs relied on the support of Volunteers.

For volunteer caregivers, their work involves transferring knowledge to family members, visiting several homes a day and working long hours. Many volunteer caregivers become the primary caregiver of the sick person. Care giving is very demanding for the family and

volunteer caregivers that can lead to physical, emotional, psychological, social and economic stress (6, 7).

In real terms, home-based care program coverage in Africa is low, and most people living with HIV/AIDS continue to be cared at their homes by members of their own kin network, without the benefit of appropriate clinical care or the support of outside organizations (5, 6, 8).

The UNAIDS (9) review of the global HIV/AIDS situation concluded that "the eventual outcome of the AIDS epidemic is decided within the community," as responses to the epidemic are primarily local—by people in their homes, neighborhoods, and communities. So we can imagine how important this HBC program is, as being part of community involvement in care and support for PLWHAs.

This study raises questions around the motivation and the challenges of volunteer home based care givers to provide service for PLWHAs as the care giving is demanding and exposes them to physical, social, economic and psychological stresses.

Rationale of the study

Despite the many advantages and the wide approval of home and community care as a favorable alternative or supplement to hospital care, efforts to know about the motivation and challenges of the volunteer home based care givers for patients with HIV/AIDS which can affect the sustainability of HBC program have been limited.

Given that most home-based care volunteers come from poor backgrounds in Addis Ababa, a city with high unemployment (10), a high prevalence of food insecurity (11), and high food price inflation (12) , volunteers may face psychosocial stress and possible declines in personal economic status which can affect their motivation to stay as caregivers. Evidences from home-based care organizations that make use of volunteers show that they usually experience high rates of attrition in other places (6).

2. Literature review

Home-based care is defined as care given to the patient within his or her own home by either formal or informal caregivers. Formal care giving is initiated and implemented through a formal structure or program which includes volunteers, and informal care-giving is provided by unpaid family members and friends (13, 14). Volunteer caregivers are members of a community who have received some form of training on the care of PLWHAs and who provide care beyond their own households and families without remuneration (1, 6).

When community support programs are developed to serve people living with HIV, they tend to rely on women as unpaid volunteers who, despite the fact that they are often as poor as or poorer than the people they are assisting, receive neither stipends nor incentives (15, 16, 17). There is little recognition or compensation for volunteers, who may be subject to exploitation and severe stress (18, 19). The recommended most successful community-based mobilization provide counseling and support for volunteers, try to provide incentives such as food or job training when possible and encourage men and boys to share the burden of care (19, 20).

Findings from previous studies in South Africa and Zambia indicated that home care programs, if properly planned, can relieve the pressure that the care of HIV/AIDS patients have on formal health care facilities (1, 8, 15). There is also evidence to suggest that such

programs have clear health, social and economic benefits for the patients, families and communities (6, 21).

But a strategy of simply downloading responsibility for care onto women, families and communities can no longer be a viable, appropriate or sustainable response. In some studies done in South Africa and Uganda, it was found out that poverty was very common among families and volunteers that they expressed bitterness with the government and the care programs (6, 16, 22). Some of them believed that the lack of food in affected households undermined the home care program to the extent that 'nothing is gained by either the volunteers or the sick people from home-based care' (6, 23, 24).

A study done in Jimma (Ethiopia) revealed that majority of care-givers of PLWHA are females and volunteers which is compatible with the findings of other studies done in South Africa and Botswana (15, 20, 22). This same study showed that majority of the care-givers have favorable attitude towards HBC as majority of them believed that HBC satisfies the care-giver and the patient(as majority of the care givers reported "satisfied" by their job) and decreases social stigma and isolation (25). In addition, they believe that people should continue participating in HBC and indeed the community is supportive of the HBC program (7, 26).

Volunteers cited the lack of employment as one of the reasons why they joined the volunteer program. Some indicated that they did not want to stay at home 'doing nothing'. Many of them hoped for a future reward from the NGOs or from the government, as they

stated it ‘perhaps someday the government will give us something for our labor’ (6). They also cited the feeling of responsibility is one of their motivations for joining to home-based care for PLWHAs (16).

Caregivers reported stress arises from the lack of appreciation and outbursts of anger from those they were caring for (15). However, volunteers often keep quiet about the physical and health problems they suffer. Reluctance to report these problems is due in part to socio-cultural values whereby the volunteers are regarded as being physically and emotionally strong because of their work. Furthermore, volunteers do not want the sponsors of their training or program officials to perceive them as incompetent. In addition, an underlying reason for keeping quiet is personal guilt about appearing to be insensitive to the difficulties of the sick person (6).

The challenge for female volunteer care givers in particular is sexual abuse (22). The risk of being raped is heightened for women who are volunteers because many of their clients live alone and could easily abuse a woman that comes to care for them without others noticing (15).

Studies showed that stigma is still very widespread in many African countries and it is having negative implications for PLWHAs, caregivers as well as the home-based care programs (25). One of the problems reported by volunteers was that of over expectation by members of HIV affected families. They expect the volunteers to bring them food that they

themselves cannot afford (16). It was also noted that families with affected members didn't welcome volunteers who visit them empty handed as they expect food parcel (6).

The valid concern regarding the ongoing sustainability of programs prioritizes the use of volunteers as a cost-saving measure. When these volunteers are themselves impoverished, this poses both an ethical and economic dilemma (16). They too have human rights and should not be exploited. Because of their poor income and lack of opportunity, such volunteers often hope that volunteering will lead to remuneration that will enable them their own life. (6, 18)

A great deal of training is invested in home-care volunteers. This gives the volunteers additional skills and confidence and in some instances, makes them employable. It is only right and natural that such people grasp any opportunity for paid employment that comes their way. This is likely to happen repeatedly. Studies in other countries showed that training new people can be as costly to the organizations as paying a nominal salary would have been. (18)

It is also true that there are many people who are able and willing to work as a volunteer.
It is only natural to feel sad and tired when one is constantly exposed to suffering and loss (22). Without support this can lead to burn out. When burn out occurs, people become pessimistic and lose their capacity to give passionate care. There is an inclination to develop a negative self-image and to become convinced that it is not possible to make a positive difference. Poverty, stigma and discrimination and the troubles of orphans and

vulnerable children exacerbate the risk of burn out for HIV/AIDS caregivers in developing countries. (18)

In a study of home-based care in south Africa, it was found that this is one of the aspects of care that community care givers found the most difficult to deal with. Coming in to households to assist with care and finding families hungry and cold, without hope of relief, is overwhelming (16). If this happens day after day, it may lead to burnout in the community care givers which can affect the quality and continuity of HBC program. (18)

Studies which are related with Community health workers (CHW) in other countries showed even if the initial idea of the CHWs assumed the existence of a pool of willing volunteers, but lack of payment has emerged as an important cause of attrition of CHWs in many programs (6). This is not to deny that much true voluntarism can be found in many communities, where people dedicate part of their time to social activities (18). Still, in truly voluntary programs, CHWs are able to work a maximum of only a few hours per week and a high turnover of volunteers is the rule (15).

Most successful CHW programs have therefore ensured that their CHWs receive adequate remuneration if their program activities prevent them from gaining their livelihood in other ways. Some evidence suggests that the possibility of professional development is an important motivating factor for CHWs, possibly improving retention (27).

In many instances CHW programs have been described in which professional health care workers saw community members as lowly aides and failed to understand the potential value of their contribution. Thus the relationship between CHWs and the formal health services often became strained, negatively affecting the satisfaction and performance of CHWs (27).

Caregivers reported that providing care in the home was a great challenge to them. It drained them both economically and emotionally. The majority of them lacked emotional and material support (23)

Studies which are conducted in other African countries showed that there are problems related with the care giving which is difficult for the volunteer care givers and they also described their reasons for being care givers. This study will look at the context of Ethiopian volunteer care givers of their motivation and challenges.

3. Objective

3.1 General objective:

-To assess the motivation and challenges of volunteer home based care-givers for PLWHA in Addis Ababa.

3.2 Specific Objectives:

-To assess the motivation of home based volunteer care-givers in providing sustained services.

-To assess the challenges of home based volunteer care-givers to provide sustained services.

4. Methods

4.1. Study design:

An ethnographic qualitative design was used to assess the motivation and challenges of volunteer home-based care givers.

4.2. Study area:

The study was done in Addis Ababa. Addis Ababa is the Federal Capital of Ethiopia and a chartered City having three layers of Government: City Government at the top, 10 Sub City Administrations in the Middle, and 99 Kebele Administrations at the bottom. The city location is between 8055' and 9005' North Latitude and between 38040' and 38050' East Longitude with total land area of 54,000 hectares. The city was establishment on November, 1887 by Emperor Menelik II and Empress Taitu. The Climate average elevation is 2,500 meters above sea level, and hence has a fairly favorable climate and moderate weather conditions. Addis Ababa is also a city for the seat of the African Union (AU) and the United Nations Economic Commissions for Africa (UNECA). (28)

Addis Ababa has an estimated total population of 2,738,248 out of which 1,304,518 are male and 1,433,730 are female(29). The HIV prevalence of the city is 7.5 with a total number of PLWHA of all ages being 156,577 and the people who are currently on ART reaches 22,885 (30, 31).

The study was conducted in the implementation area of Hiwot HIV/AIDS Prevention, Care and Support Organization (HAPCSO) which was established as a local NGO in the capital

of Addis Ababa in 1999 by Nurse Tibebe Maco as an indigenous, community-based response to the HIV/AIDS epidemic (32).

There were about 10 local NGOs working on HBC program in Addis Ababa. Some organizations had volunteers without any payment and some with incentives. Other organizations had employed people to carryout HBC (33).

4.3. Study population:

The study population include volunteer home based caregivers who are giving the service (active) and dropouts, nurse supervisors and community workers under Hiwot, local NGO working on HIV/AIDS prevention, care and support in the ten sub cities of Addis Ababa. The HBC program was started on Sep. 2003. Since then around 1400 volunteers have been recruited. Previously volunteers were recruited to serve for a total of 18 months and there were recruitment of 600 volunteers every 18 months. Recently the organization decided to make the service time 24 months because of less burden and less burn out due to the patients' health status after ART. The focus of the HBC program is mainly on ART adherence and SRH (sexual and reproductive health). The total number of volunteer care givers under the organization currently is 527 of which 498 are female and 29 male. The volunteers are recruited through indigenous community organizations, iddirs and the organization. Volunteer caregivers are trained for three weeks and typically work for a period of 24 months, caring for 20 non-kin patients each, under the close supervision of an iddir and the local NGO. Caregivers receive some small benefits to reimburse their transportation expenses. The volunteers walk to patients' house within their own vicinity. The organization provide car for transporting patients whenever possible or the volunteers

should pay and refunded later. There are 8117 beneficiaries under the organization for HBC out of which around 7305 (90% of the beneficiaries) are on ART. The community workers are 24 and all of them were promoted from volunteer care givers. They assist the nurses and supervise volunteers. There are a total of 13 supervisor nurses currently.

4.4. Sample size and Sampling technique

Purposive heterogeneous sampling was used to select the study subjects based on sex, educational status and length of service. Drop outs and community workers were also included. The sample size was determined by level of saturation.14 in-depth interviews and three FGDs were conducted. The 3FGDs were conducted with 6 volunteer care givers, in which 4 were female and 2 male, 6 nurse supervisors in which 4 were female and 2 male and 6 community workers in which 5 were female and 1 male. The study subjects were selected from Hiwot, local NGO which is working on HIV/AIDS prevention, care and support in the 10 sub cities of Addis Ababa. The investigator comes up with conducting 14 in-depth interviews by conducting in-depth interviews until saturation level was reached. The investigator included the community workers as they were volunteers previously and their close relationship with the volunteer care givers. The sample size was determined by level of saturation/redundancy.

4.5. Data collection

Qualitative data were collected from April 1- May 30, 2009. Data were collected using open ended interview guides for in-depth interviews and FGDs from volunteer care givers, nurse supervisors and community workers who are working under Hiwot, a local NGO

working on HIV/AIDS prevention, care and support in the ten sub cities of Addis Ababa. 14 in-depth interviews and 3 FGDs were conducted. Two in-depth interviews were conducted from each category as; new comers, veterans, drop outs, male volunteers, female volunteers, high school completes and community workers. Three FGDs were conducted among volunteer care givers, community workers and supervisor nurses. The data were collected on the motivation of volunteers, their expectation, what keeps them motivated, on the benefit of care giving, their reason for dropping out, challenges and on the need of improvement.

The rationale of the FGD with the nurse supervisors was to get their opinion on the motivation, expectation and challenges of the volunteers and of their own experience of the challenges of HBC as they work closely with the volunteers as supervisor nurses, trainers and recruiters. The FGD with the community workers is to get information on the above issues of the volunteer care givers and their own experience as a volunteer home-based care givers as all of the community workers were volunteer care givers previously. They work closely with the volunteers now as supervisors and recruiters.

All in-depth interviews were done by the investigator. The in-depth interviews were done mostly in one office room of HIWOT organization (a site office which has one staff who was kind enough to leave the room for the interview) which was comfortable for keeping privacy and, two in-depth interviews were conducted in a quit comfortable room at a research institute at ALERT hospital as the respondents were employed there so it was done there for their convenience. The FGD was conducted by the principal investigator as

moderator and one research assistant that has a Masters degree in Biomedical Science as a note taker. Care was taken while selecting convenient place for the interview as well as FGDs.

The FGD participants were selected with the appropriate person. For the FGD with the volunteers and community workers one community worker helped the investigator in selecting the participants and for the nurse supervisors the nurses' immediate boss helped the investigator in the selection of participants. The FGDs were conducted in a hall of the organization with a U-shape sitting pattern to facilitate the discussion of the participants.

Both in-depth interviews and FGDs were tape recorded after the participants gave consent and transcription was done simultaneously which helped to know the saturated questions and to add new questions as the need arise (emergent design). The duration of in-depth interview was from 32 to 57 minutes. An hour of audio interview took about a day for transcription. The FGD took from 72 to 102 minute. The participants were so comfortable that they were relaxed to talk for longer time. All the participants of the study were given a 20 birr compensation for their time and transport expenses.

4.6. Data analysis

The tape-recorded qualitative data obtained from the FGD and in-depth interviews were familiarized through repeated listening of the audios. The data were then transcribed. The transcribed data were translated into English by the investigator. There were identified

(pre-defined) themes under which data were collected and the investigator also allowed themes to emerge from the data.

After complete transcription and translation of the interviews, data clearance was done by listening and re-reading the interviews repeatedly. The cleared transcribed data which was on word document was changed to plain text and were exported to open code 3.4, a computer soft ware for handling qualitative data, and then it was open coded, emerging concepts were delineated, conceptual coding were done and cluster of concepts were formed to develop analytical categories. The abductive research process allowed to compare response across respondents and derived a core category, a modified grounded theory approach. Grounded theory allows deeper exploration and identifying context-free theory (34). Analysis focus on finding answers to questions: why do individuals volunteer for HBC? How do they maintain their commitment over a longtime? And why do they quit providing HBC?

4.7. Data quality

To ensure the data quality the in-depth and FGD guides to collect the information were developed carefully and with close discussion with advisors. Participants were explained about the importance of their genuine information for the study and the implications it will have beyond by stressing on the confidentiality of the data they will give to the investigator.

The use of the two interview methods and different data sources will increase the trustworthiness through triangulation. The investigator ensured careful selection of informants with assistance recruiters which are workers in the organization and have been working with the volunteers for more than 18 months. The prolonged time spend with the volunteers helped the investigator to build trust with the study participants. The investigator knew the study participants from a previous study at which she worked as a research assistant.

Ethical consideration

Ethical approval was obtained from Ethical Review Board (ERB) of University of Gondar. A support letter from Addis Continental Institute of Public Health about the purpose of the study was used to facilitate the data collection. A verbal consent was obtained from each respondent before interview. The research participants were explained about the purpose of the study, the type of questions which are likely to be raised, the anonymity of the informants, their right to withdraw from participation and not to answer questions which they are not comfortable with any time and the possible risks and benefits of participation in the study. To maintain confidentiality the tapes and the transcripts were handled only by the investigator and unique codes were used for identification. The tape records (audios) were destroyed by the investigator after the analysis was finished. Moreover the study participants were reimbursed 20 birr for their expenses at the end of the interview.

Definition of terms

- Home-based care (HBC) is defined as care given to the patient within his or her own home by either formal or informal caregivers.
- Volunteer caregivers (VCG) are members of a community who have received some form of training on the care of PLWHAs and who provide care beyond their own households and families without remuneration.

5. Results

A total of 32 individuals participated in the study out of which 75% (24) were female and 25% (8) male. The participants were composed of 18 volunteer home-based care givers, 8 community workers and 6 supervisor nurses. The majority of the participants (84.3%) were between the ages of 18-35 years and the rest were between the ages of 36-47 (15.7%). The educational status for volunteers raged from elementary completes to 10+2 completes. Out of the 32 study participants 56.3% were married and 43.7% were single and divorced. Regarding the length of service 72.2% of the volunteers care givers served for over 26 months and 27.8% of them served for 18 months.

During analysis three distinct phases were identified in the provision of HBC: the entry, continuation, and ending (quitting) phases. The factors that motivate individuals in different phases vary.

Entry phase (why do individuals volunteer for HBC?)

The most dominant motivating factor to join volunteer HBC program before the start of ART was the suffering and death of beloved ones and people in the neighborhood. During that time patients were critically ill and a lot of people died because there was no treatment. The scene at their home and their area motivated people to join HBC to help patients. It was not only the suffering and death of patients but there was shame, anger and disapproval from family members that made the stigma and discrimination worse. The

reactions patients get from their family members and the community as a whole was not supportive and their situation made people feel responsible and help them.

The other motivating situation for volunteers was the presence of many patients who had no one to care for them as most of them were discriminated by their families and live in a rented house hiding. The elevated number of bed ridden patients before the coming of ART was another motivating situation for people to volunteer as home-based care givers. At that time the patients were not taken to hospital as the hospitals were sending patients back home where there was no hope except to wait for their death.

The participants also pointed out that the motivation for serving the patients was from feeling of humanity and concern as a fellow citizen. The condition at that time tested the peoples' humanity. HIV/ AIDS made things look against nature as mothers throw out their children from their house at the time their children needed their care most. These events were motivating for people to care for those patients free and it was impossible to think about being paid at that time. The condition of the patients at that time was overwhelming that the volunteers were not in a position to think about money and incentives.

Table1. Motives and challenges of HBC providers for PLWHAs. Addis Ababa, Ethiopia. June 2009

Phases	Motives	Challenges
Entry	Loss of beloved ones Feeling of humanity Avoiding idleness Future job opportunity Fetching benefit Stigma & discrimination	Work load Poverty of patients Change of patients' needs Stigma and discrimination Outbursts of anger from patients
Continuation	Mental satisfaction Full filling spiritual demand Positive self image Job opportunity Communication skill Decreased work load	Inadequate support Poverty of patients and volunteers Poor relation with patients Patients dissatisfaction False accusation Time taking/Demanding Misconception about volunteers
Ending	Got paid jobs or went to Arab countries Increasing cost of living Inadequate support Change in patient behavior (single men) Dissatisfaction with relationship with patients and supervisors	PLWHAs expectation Lack of recognition Patients anger expression Pressure to make financial contribution Dependency of patients on volunteers Less cooperation from hospitals

The death and suffering of loved ones, the presence of many bed ridden helpless patients and the stigma and discrimination of patients by close family members and community was the core motivating factor for care givers who volunteered to serve PLWHAs before the start of ART for free without feeling tired and burned out.

> "*There was one patient of mine who had no one to care for her at home. Her neighbors tie a bottle of water on her chest when they went out. She couldn't move. The bottle is kept open on her chest. When she wanted to drink the water, she pushed the bottle from the back and the water flew to her mouth."* (A community worker who served as volunteer care giver before the start of ART)

Like the volunteers before ART, the volunteers who started the care giving after the coming of ART also claimed that the suffering and death of loved ones made them to contemplate the need of other patients to be cared and helped as many participants described their motivation as being; to help fellow people, to get mental rest and do something which can bring a positive difference. Although the motivation of many volunteers is similar with the previous volunteers, there is a change in the motivating factors as patients' health status was improved after the start of ART.

The other frequently stated motivating factor was seeing the home-based volunteer care givers help patients in their house or their area. The first volunteers were motivated without having a model but by the situations of patients that time. However their work was a motivation for the following volunteers. The current volunteers used to talk with former volunteers and the volunteers use to tell them what they saw and how they helped people. The volunteers were able to know the real situation of the condition that time.

There was a time in the volunteers life at which time they were discriminating patients themselves which causes resentment as they learn they could have done different to save lives if not to help for a peaceful death. The anger and the gilt they felt motivated them to join HBC program and help other people who are discriminated by family members and the community.

There were other motivations for volunteers after the start of ART as; preferring to join HBC and help patients than sitting home idle because the patients were relatively well and there was less work load. The wheat and oil which used to be given to both patients and volunteer care givers when ART was first started was also one of the motivating factors for volunteers who joined that time. The thinking that the work can be used as a reason to go out of their house encouraged people to volunteer to join HBC. There is also another reason for joining; the hope volunteers had for future remuneration.

The first home-based volunteer care givers (those who volunteered to care for PLWHAs before the start of ART) were employed by the organization as community workers which became one of the motivations for the following volunteers.

The other emerging motivating factor for volunteers was the job opportunity the volunteers are getting in different organizations. Volunteers are being given priority in hospitals and the organization under which they are working for employment. The certificate is very important for future job opportunity.

Even if there are people who want to volunteer and serve patients there are also people who come only for the benefit and then disappear once they get what they came for. They come for the money given during the training, which is given to volunteers before they start HBC. Some come for taking the training because the training is basic and standard and others following their friends to spend their time.

The motivation of volunteers for joining HBC changed after the start of ART. When ART was started patients started to get well and the suffering and death as well as the stigma and discrimination decreased. This situation diminished the intrinsic motivation of people. Volunteers were motivated by different benefits in addition to intrinsic motivation. The motivation was the wheat and oil which was given for volunteers, to avoid idleness, for future job opportunity and looking former volunteers.

> "*Now many volunteers are getting jobs because they have the certificate from this organization. To your surprise people are*

now very interested to join and they are asking me about registration time." (One volunteer)

Continuation phase (How do they maintain their commitment?)

There were three groups related to the benefit volunteer care givers received in kind or money. One group was the group which worked before the emerging of ART and has got only 50 birr transportation allowance per month. The second group being the group which started the care giving after ART was started and that time there was a 45 kg of wheat, 3 liter of oil and 50 birr transportation allowance per month. The third group was the group working now and which started the work knowing that there is only a 50 birr transport allowance.

The motivation of volunteers, before ART, to continue care giving despite the many challenges they faced, was the mental satisfaction they got when patients became relatively well with the care they gave them. The patients' happiness and gratitude kept the volunteers motivated to help their patients, which created a sense of positive self image among volunteers. At that time there was no food support for the care givers and the patients unlike the volunteers who started to give care after the surfacing of ART.

The intimacy the patients had with the care givers was another situation that kept volunteers motivated. The patients were close to care givers than anyone, even their family. The discrimination and disapproval from the family and other community members made the patients to seek care and love and became grateful when they get that.

Most volunteers believe that the benefit of being a volunteer care giver is knowledge, ability to communicate with people and being close to God. The mental satisfaction, the happiness, the need of fulfilling spiritual demand and the positive self image for themselves kept volunteers motivated to serve PLWHAs despite the many challenges before the start of ART.

> "*The benefit of being a volunteer is first the knowledge. Secondly, when I help someone near death and make him well that time I feel happy more than anything. When I be there for people who has no family I feel very good. I am happy with that*." (A community worker who served as a care giver before the start of ART)

The benefit of volunteer care givers shifted with the time. The benefit mentioned by most former volunteers was the mental satisfaction and a positive self image. Then there came a time the volunteers got food support which was additional benefit for them. Currently the benefit was contributed by the job opportunity the volunteer care givers were getting at Hospitals.

The decrease in the work load, as more and more patients become ambulatory due to ART, made people to be more motivated to continue as care givers on top of the certificate at the end which is important for getting job. Many people want to be volunteers now because they know there is a chance of getting employment after working as a volunteer care giver.

> *"People hear about the job opportunity the other volunteers got and they want to join because they want to get employed. People are now eager to join and get certificate which is important for future job opportunity*." (A volunteer)

The care givers also mentioned their reward in the future from God as job opportunity or the life satisfaction as the benefit they get from being a home-based care giver. There is also a sense of positive self image as there is trust and acceptance from the community. The care giving experience has a big value in changing the personal life of volunteers as well as their families. The volunteers also brought a change in their community on different aspects of HIV/AIDS related misconceptions.

> *"Because volunteer care givers took the training and do the volunteer work they got another job. They are supporting their family now. They started with volunteer work and get employed."* (A volunteer)

Being a volunteer care giver helped volunteers to go out of their house and meet with people and helped them in their communication skills. There were also people who were doing both the care giving and their paid job together because they didn't want to drop out.

The volunteers after the start of ART were kept motivated mainly by the future job opportunity in addition to the mental satisfaction, happiness and the communication skill they got from being a care giver for PLWHAs.

Ending/quitting phase (why do they quit providing HBC?)

Most volunteers are happy to work as a care giver for free however the current increase in the cost of living is a reason which is making life difficult for them to work without having some income. Despite the challenges they are facing due to the living situation, volunteers are convinced that the absence of monetary benefit is not comparable with the mental satisfaction and the positive self image they got from being a care giver.

The monetary benefit of being a care giver is very small and it is not enough. Volunteers are given a 50 birr transportation allowance but they spend more than what they have been given while they were calling patients and supervisors for messages and for transportation. They also spend the money when they visit their patients and found them in need of money.

Many volunteers drop out when they got other paid jobs or when they went to Arab countries for better payment. As the money given for transportation for a month is very small people leave whenever they get better payment. Many people drop out not because they dislike the work but they have pressure either from family or they were pushed by the rise in cost of living. The small incentive they are given was one of the reasons volunteers loss their interest in continuing the care giving.

> *"There was one female volunteer care giver who went to Arab country. She was a very strong and model volunteer. She was a hard worker. She worked more than any one of us but one time without anyone's suspicion she went to Arab country. Even if she loved the work she left. Sometimes while you want to work life will force you to discontinue."* (A volunteer)

Many volunteers don't want to do the volunteer work for long because they need change in their life. They want to have their own income and be able to help their families. Young people who are living with their family said that even when family doesn't say anything after some age it is uncomfortable to live with them without any contribution. So after working for sometime as a volunteer they want to search for other paid jobs.

The other reason for dropping out is a bad communication with supervisors and patients. Some drop out to go to school. There are also people who join for some benefit and after they got what they want they drop out. There were also opinions that dropping out was related with the weakness of the volunteers but not with other tangible reasons.

The volunteers believed that there were drop outs which were significant in number that increased the burden on them as the patients under the drop outs were distributed among them. But the supervisor participants disagreed as they believed that the number of drop outs was not significant and was not compromising the HBC program.

There was a decrease in the satisfaction of patients from the care they got as the care they wanted is changed when they got well. Patients expressed their anger on volunteers. There was a lot of complain and intolerance among patients. The patients' expectation was so high that it prevented them from appreciating the things which was done by the volunteers. The volunteers said that there was no much work lately. Most of the time what the volunteers do was to give advice for patients and pass messages if there were any. The above situation of patients was contributing for the volunteers feeling of less appreciated and not being able to making a positive difference.

There was a misconception about volunteers. Patients think that volunteers are paid and they have obligations to help them even if she/he is healthy and can manage her own house work. There was dependence of patients on the volunteers. The patients' false accusations and their lack of satisfaction from the care they were given was one of the challenges the current care givers were facing.

> *"The problem is whatever you do for the patients, they don't acknowledge that. For example if one patient get sick you go there and cook food, wash clothes and you do many things but he doesn't say you did that for him. They accuse you instead."*
>
> (A volunteer)

The shortage of money for transportation was another challenge. The volunteers were refunded the money after they spend for patients' transportation. But the volunteers had a problem of money themselves which forced them to borrow and spend for the transportation. The problem they mentioned was the refund process take time and put them in problem.

It was clear that volunteer care givers face a considerable amount of challenge but there was a shift in the type of challenge. The challenges related with the nursing care of the patients and stigma and discrimination decreased. But there was a change in the need of patients as well.

The other challenge was when caring for single male patients. The ART improved their health and people were going back to their routine behaviors. Patients started drinking alcohol and that was causing a challenge for female volunteer care givers to care for single men patients. *"Home based care is a little difficult for single male patients."*

The study participants agreed on one thing unanimously as a challenge that was the lack of recognition the volunteers of HBC was having from the government as well as from community. The participants believed that they didn't get the kind of recognition they should have. Even if HBC plays an important role in the prevention of HIV/AIDS as well as in the care and support the recognition of volunteers and other workers was minimal.

There is a change in the challenges of HBC as in the motivation. Before the coming of ART the biggest challenge was the lack of awareness and stigma and discrimination from close family members of patients and the community. The other challenge was the death rate of patients. Whatever care the care givers did that time it was a time that they bury most of their patients which made their work very stressful.

> "*We visit the patients, we care for them but finally they don't get well. It was one from many patients who may got well. After doing all that, they die. And that was stressful for us and we were thinner physically.*" (A community worker who served as a care giver before the start of ART)

There were many challenges in previous time because many people were bed ridden and there was problem of transportation. The patients also had economic problem. But now a day's as patients are well and start to help themselves they are not looking for the kind of care they used to get when they were bed ridden, rather they want financial support. The patients who were bed ridden at the time, when the ART was unavailable, needed care, love and company most.

Even if there were many challenges the most dominant was the poverty that patients as well as volunteers were facing. The poverty was so deep that it made volunteers to look for other ways to win their life. The poverty of patients was also a challenge for volunteers as it was very stressing for care givers being unable to help the patients financially. The

poverty of the patients as well as the volunteers themselves is the biggest challenge which was affecting volunteers' motivation for continuing care giving.

> "*The word poor can't express the patients' situation. When children are back from school they don't ask for food because they know that there is nothing at home*." (A nurse supervisor)
>
> "*I had one client who had one orphan child. The child was mentally retarded and was 17. When I first entered to her house he looked like a dog tied in the corner of the house. He didn't seem a human being. She tied him with rope. The rope was deep in his flush. He was in a sitting position for so long that he couldn't stand. I was very scared when I saw him. I was not ready to see that. After that I made the mother to untie him and I did many things for him. When I asked her why she tied him she said "there is no one to keep an eye on him when I go out to collect leaves for fuel and selling." because the child is not HIV positive he is not included in our organization for food support. If he was positive he could have been given food support. So they say it was better if he was positive."* (A nurse supervisor)

As the cost of living rises the little payment became a challenge for volunteers. The rise in the cost of living was the one big factor which was making people to drop out whenever

they get better paying jobs or when they got a chance of going to Arab countries. The participants unanimously agreed that the work of volunteers has burn out and there is less care and protection for volunteers. They also acknowledge that there is less cooperation from hospitals which can affect the motivation of volunteers negatively.

6. Discussion

This study tried to assess mainly the motivation and challenges of volunteer home-based care givers as the volunteers themselves come from impoverished situation. The study showed that the motivation of volunteers has been changing in general. In the past volunteers were motivated mainly by the suffering and death of close family members, friends and neighbors. They were also motivated by the high number of bed ridden patients, the stigma and discrimination and feeling of humanity. Even if the following care givers after the start of ART were motivated by the same cause as by the suffering and death of loved ones but there were also other reasons for being motivated. The other reasons were the food support which was given that time, to avoid idleness and the job opportunity the previous care givers got. The new emerging motivating factor is the job opportunity the volunteers are getting at hospitals.

The above findings showed that there is a decrease in the intrinsic motivation of volunteers due to the improved health status of patients and the rise in the cost of living. Even if the number of the volunteers may not decrease for the reasons above there will be a question whether the quality of care could be maintained.

From the study one thing is clear, that is the motivation of volunteers to join HBC is many and changing with time. The change comes from improvement of patients' health status due to the coming of ART and the rise in the cost of living. The ART improved the health status of patients which decreased the suffering, death and number of bed ridden patients a

study done in Rwanda at 2007 on met and unmet palliative care need of PLWHAs revealed the same (35). The decrease in the suffering, death and number of bed ridden patients decreased the intrinsic motivation of volunteers. The former volunteer care givers saw many sufferings, many deaths and many bed ridden patients which motivated them to volunteer for HBC compared with the current volunteers.

The volunteers agree on one thing; the mental satisfaction and the positive self image they got from working as a volunteer was the biggest benefit and it was the one big thing which kept them motivated which synchronizes with the finding of a study done in South Africa at 2002 on the practice of community care givers in a Home-based HIV/AIDS project (1). But the level of mental satisfaction has been decreased as the patients become well and their need changed. The patients need changed as their health is improved which created a space between the volunteers and patients. It created less satisfaction among patients as well as volunteers which contributed for the lack of gratitude and intolerance of patients for the volunteers which was against the finding of other study in South Africa as it stated the success of volunteers in satisfying the patients (1). Most of the volunteers agreed that the satisfaction, gratitude, love and respect from their patients are important to continue the care giving.

The change in the motivation of people is alerting that the rise in the cost of living is ripping the intrinsic motivation of volunteers and making them to look for options and benefits to join and continue the care giving which is only natural and expectable. Even if there are people who are willing to volunteer, there is a decrease in the intrinsic motivation

of people (18). The volunteers are derived by the poverty they are in to join to HBC so that they will have an opportunity to win their own life.

Even if there is a change in the motivation of people to be care givers for PLWHAs, the suffering and death of close family members and loved once remained the top motivating factor to join HBC. There was a real motivation to help people because the volunteers didn't turn their face from the care giving when they heard those talks about patients rather they joined and faced the whole thing themselves. It is also clear that things were improving in relation with patients' health status and situations which decreased the work load of caring for PLWHAs.

The rise in the cost of living was challenging for both volunteers and care givers. The volunteers were faced a double challenge as in one side their own life problem and in other the problem of their patients. This is also compatible with a book written at 2003 on Home-based HIV/AIDS care (18). The problem of volunteers was pushing them to look for options for income. As the study participants revealed most drop outs are either because they got jobs or went to Arab countries for better payment. This showed that there was a greater pressure from the increased cost of life on the peoples' motivation to work as volunteer home-based care givers as they should look for ways to full fill their own need.

The sustainability of HBC doesn't seem to be affected by the number of volunteers at least for some time in the future as more and more people are coming to volunteer mainly due to the job opportunity the former volunteer are getting. But it is clear that people who don't have real interest can't do the care properly and they can burn out easily. The

misunderstanding of patients and the lack of gratitude and appreciation is another biggest challenge for volunteers which break the chain of motivation that keep them in the care giving service.

The patients suffering and the work burden was decreasing through time making the work of volunteers easy in terms of physical stress but the changes in the health status of patients and the expensiveness of life made a change in patients' need which increases the stress for the volunteer care givers.

Even if the discrimination was not as severe as before it was still there and it was a challenge for both patients and volunteer care givers as found out by UNAIDS 2004 report on care giving (24). People were not willing to involve in the help especially family members. Patients are still found hidden because of the discrimination from family members.

A book on Home-based HIV/AIDS care;2003 showed the training and experience of care givers is making them employable which in one way increases peoples' interest to be involved in home-based care giving but at the same time has a risk of attracting people who only want it to get the final job opportunity. This can made communication with patients and supervisors difficult and endanger the quality of care (18).

Many patients are now ambulatory patients because of ART and it is mandatory to involve them in work to support themselves than make them depend on support as another study done in Rwanda on met and unmet palliative care need of PLWHAs reveled there is unmet

need of PLWHAs specially financially which can made them eligible to be involved in work (35). Participants suggested that the support bed ridden patients receive now is not enough for them. So as long as PLWHAS are healthy and capable of working it is better to involve them in different work activities than continuing the support as this may lead to dependency and loss of interest for work. There are some initiatives now and participants suggested it should be expanded. As the book on Home-based HIV/AIDS care;2003 and a joint report of UNAIDS/UNFPA/UNIFEM 2004 on women and HIV/AIDS revealed that the little recognition and compensation of volunteers and the treatment they got from health professionals affected the motivation of volunteers negatively (18, 19)

Strength of the study

The investigator was working with the volunteer care givers before her study with another researcher as a research assistance which made the communication easy with the volunteers as the investigator spend quit a long time with the study participants (prolonged engagement). The study design is also suitable to answer the study objectives.

The in-depth interview respondents were selected by community workers whom the investigator talked with about the criteria to follow to select the respondents among the volunteers. The criteria were being able to meet the category group and able to express themselves but not dominant. The community workers know the volunteers very well because they have worked in close communication for over 18 months and the investigator has no doubt that they followed the guide to select the volunteers.

The investigator was the one who did the in-depth interview and was the moderator for FGDs. The investigator was careful not to judge respondents and she involved all the FGD participants during the discussion. Care was taken to keep the confidentiality of the respondents by using codes instead of names and a quiet comfortable office room was used for data collection.

Limitation of the study

The limitation is the study included only one NGO. The reason was one of the local NGOs, which were proposed for data collection, asked the investigator to have a written consent from the respondent volunteers after data collection which will be given to the organization. The investigator tried to explain them the situation but they insisted on having the signed written consent. The data collection from that organization was cancelled for ethical purpose.

7. Conclusion

- Poverty encourages volunteers to HBC due to perceived immediate and long term benefits in economically disadvantaged population group. Poverty and joblessness lead people to volunteer; and when they fail to overcome them – they quit.
- The change in the patients' need after the coming of ART and the rise in the cost of living is affecting the motivation of volunteers negatively.
- Less compensation from the organization and less recognition from the hospital health professionals, the government and the community as a whole of volunteers is one factor which is affecting the motivation of volunteers negatively.
- There is unmet financial need of patients and volunteers which should be discussed openly.
- Lack of cooperation and support from hospitals and other administrative offices for volunteers and patients as well.

Recommendation

1. The financial capacity of patients and volunteers should be strengthened by Home-based care programs.
2. There should be recognition for volunteer home-base care givers from the government and the community
3. Community mobilization should be expanded so that all community members feel responsible and participate and share the burden on volunteers as this is not only the work of volunteers and NGOs.
4. HBC programs should investigate the needs of patients and volunteers to take appropriate measure
5. Organizations involved in the use of volunteers should consider the rise in cost of living as one factor which can affect volunteers' motivation.

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9. Annexes:

Annex 1. Oral Consent form for interviews

My name is Selamawit Shifferaw. I am a Masters student at a JOINT MPH program of Addis Continental Institute of Public Health and University of Gondar. I am doing a thesis on motivation of volunteer caregivers to provide long term service for PLWHAs in Addis Ababa. I will interview volunteer care givers, nurse supervisors and social workers to assess the motivation, challenges and willingness to provide long term services of volunteers for PLWHA in Addis Ababa. The interview will include questions on motivation, challenges and willingness to provide long term service for PLWHAs. The interview may take about 45-60 minutes.

The information you give me will be kept confidential and your name and address will not be recorded to protect the confidentiality. I will only use code numbers for identification. All the things said during the interview should be tape recorded. The tape recorded information will only be used for the research purpose but not more. You have the right not to answer for the questions which might be inconvenient for you and quit from the interview at any time. There is no potential risk from being part of the study. However, your information is very important for the research. Again I would like to confirm to you that all your answers are confidential and used for research purpose only.

Would you like to participate?

If yes continue

If no stop it here

Date _____

Name of interviewer _____

Signature _____

Annex 2. Oral Consent form for interviews (Amharic)

የስምምነት ቅጽ /የቃለ መጠይቅ /

ስሜ ሰላማዊት ሽፈራው ይባላል። አዲስ ኮንቲኔንታል እና ጎንደር ዩኒቨርሲቲ በጋራ በሚሰጡት የማስተርስ ፕሮግራም ተማሪ ነኝ። በበጎ ፈቃደኛ የቤት ለቤት ተንከባካቢዎች ዙሪያ ጥናት እየሰራሁ ነው። ጥናቱም በጎ ፈቃደኞች ምን እንዳነሳሳቸው ለረጅም ጊዜ ለማገልገል ያላቸው ፈቃደኝነት እንዲሁም አገልግሎቱን ለመስጠት እንቅፋት ስለሚሆኑባቸው ነገሮች ይጠይቃል። ይህ ቃለ መጠይቅ ከ45 እስከ 60 ደቂቃዎች ያህል ሊፈጅ ይችላል።

አሁን አንቺ የምትሰጪኝ መረጃ ሚስጥራዊነቱ የተጠበቀ ነው። ሚስጥራዊነቱን ለመጠበቅ ስምሽ እና አድራሻሽ አይመዘገብም። የምጠቀመው የሚስጥር ቁጥር /ኮድ/ ነው። በውይይቱ ጊዜ የሚባሉት ሁሉም ነገሮች በቴኘ መቀዳት አለባቸው የተቀዳው ውይይት ለጥናቱ አላማ ብቻ የሚውል ነው። መመለስ የማትፈልጊውን ጥያቄ አለመመለስ ወይም ከውይይቱ በፈለግሽ ሰዓት ማቋረጥ ትችላለሽ።

ነገር ግን የምትሰጪን መረጃ ለጥናቱ በጣም አስፈላጊ ነው። በጥናቱ በመሳተፍሽ የሚከተል ጉዳት የለም። በድጋሚ ላረጋግጥልሽ የምፈልገው ውይይቱ ሚስጥራዊነቱ የተጠበቀ እንደሆነ ነው።

በጥናቱ ለመሳተፍ ፍቃደኛ ነሽ?

አዎን ካለ ይቀጥላል

የለም ካለ እዚህጋ ይቆማል

ቀን _____

የጠያቂ ስም _____

ፊርማ _____

Annex 3. Oral Consent for Focus Group

Name of research study: assessment of the motivation and challenges of volunteer home based care-givers for PLWHA in Addis Ababa.

Principal investigator: Selamawit Shifferaw (BSc.)

We would like to talk to you about taking part in discussion group that will be conducted to get information on motivation, challenges and willingness of volunteer home based caregivers to provide service for PLWHAs in Addis Ababa.

There is a trained leader for the discussion and if you agree you will be in the discussion for about 60-90 minutes. Your participation is voluntary and you can quit being in the group at any time. We are asking you to participate because we are talking to people who are volunteer home based care givers of PLWHAs under Hiwot NGOs.

There is a small chance that what people talk about in the group will make you feel uncomfortable. There is also a small chance that others in the group may tell someone you were taking part or report what you said.

The groups will be tape recorded with voices only. The tape recorded data will be handled by the investigator and will be used only for research purpose. Note taker will write down opinions. We will not record your name. We ask participants not to reveal information they may have heard in the group but we cannot guarantee that. You can contact the investigator with the following number if you have any question, 0911 92 02 62

You will be paid 20 birr for taking part in this research.

Moderator:

I have reviewed the fact sheet with the research participants, and they have fully agreed to be in this focus group discussion. I further agree to keep confidential anything that is said in the discussion group.

Moderator's name	Moderator's signature	Date

Annex 4. Oral Consent for Focus Group (Amharic)

የስምምነት ቅጽ (ለግሩፕ ውይይት)

የጥናቱ ርዕስ፡ ለHIV/AIDS በሽተኞች የቤትለቤት ተንከባካቢ የሆኑ በጎ ፈቃደኞችን ረኸርም አገልግሎት ለመስጠት ስላላቸው ተነሳሽነት የሚዳስስ ጥናት

ጥናቱን የሚያጠናው ሰው፡ ሰላማዊት ሽፈራው

እኛ ከእናንተ ጋር በጋራ ውይይት ለመሳተፍ ትፈልጉ እንደሆነ ለመነጋገር እንፈልጋለን፡፡ የጋራ ውይይቱ የሚደረገው በበጎ ፈቃደኛ የቤት ለቤት ተንከባካቢዎች ዙሪያ ከHIV/AIDS ጋር ለሚኖሩ ሰዎች ረኸርም ጊዜ እክብካቤን ለማድረግ ስላለው ተነሳሽነት፣ ፈቃደኝነት እና ችግሮች ነው፡፡ ውይይቱን የሚመራ አንድ ሰው አለ ውይይቱ ውስጥ ለመግባት ፈቃደኛ ከሆኑ ከ60-90 ደቂቃ ሊቆይ የሚችል ውይይት ይኖራል፡፡ ተሳትፏቸሁ በፈቃደኝነት ነው ከውይይቱ በፈለጋችሁ ጊዜ ማቋረጥ ትችላላችሁ እናንተን በዚህ ውይይት እንድትሳተፉ የጠየቅናችሁ የምንጠይቀው በህይወት እና መድህን ድርጅት ስር ያሉትን የበጎ ፈቃደኛ ተንከባካቢዎች ነርሶች እንዲሁም ሶሻል ወርከርስን እየጠየቅን ስለሆነ ነው፡፡

በውይይቱ ጊዜ ሰዎች አንቺን ደስ የማያሰኝ ነገር ሊናገሩ ይችላሉ እንዲሁም በዛ ውይይት እንደተሳተፍሽ ለሌላ ሰው ሊናገሩ ይችላሉ፡፡ውይይቱ በቴፕ ይቀዳል የተቀዳው ውይይት በጥናቱ ዋና ተመራማሪ ብቻ የሚያዝ ሲሆን ለጥናቱ አላማ ብቻ ይውላል፡፡ በውይይቱ ጊዜ አንድ ማስታወሻ የሚይዝ ሰው ይኖራል፡፡ ስማችሁን አንመዘግብም ተሳታፊዎች በሙሉ ውይይቱን ወደ ውጪ እንዳያስተላልፉ እንጠይቃለን ግን ያ ሙሉ በሙሉ ይሆናል ብለን ዋስትና አንሰጥም፡፡

በመጨረሻም በዚህ ውይይት ስለተሳተፋችሁ 20 ብር ይከፈላችኋል፡፡

አስተባባሪ

ይህንን መረጃ ከውይይቱ ተሳታፊዎች ጋር አብሬ አይቻለሁ እናም በጋራ ውይይቱ ላይ ለመሳተፍ ሙሉ በሙሉ ፈቃደኛ ሆነዋል፡፡ እኔም ሚስጥራዊነቱን ለመጠበቅ ተስማምቻለሁ፡፡

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የአስተባባሪ ስም **የአስተባባሪ ፊርማ** **ቀን**

Annex 5. In-depth interview guide for volunteer caregivers

1. What motivates you?

- What motivated you to become a care giver? Why did you become a volunteer care giver?
- How do you describe volunteering? What is volunteering?
- How did you first find out about HBC? Who told you? And what was the information you heard?

2. Have you achieved your expectation(are you satisfied with your work as volunteer)

- What was your expectation when you start giving the service? Did you get your expectations?
- What do you feel about the care giving now? What makes you feel that way?
- Do you want to continue providing care for PLWHAs? Why? For how long?
- Have you ever thought about quitting the care giving?

3. Do you encourage others to volunteer

- Do you encourage people to become volunteer care givers?
- Why do people drop out from HBC programs?
- What do you think about the sustainability of this home based care programs by volunteers?

4. What are the challenges in home-based care giving

5. What need to be improved

Annex 6. In-depth interview guide for volunteer caregivers (Amharic)

የቃለ መጠይቅ መመሪያ (ለበጎ ፈቃደኞች)

1. **ምን አነሳሳሽ**

- ተንከባካቢ ለመሆን ምን አነሳሳሽ? ለምንድን ነው ተንከባካቢ የሆንሽው?
- በጎ ፈቃደኛነትን እንዴት ትገልጪዋለሽ? በጎ ፈቃደኛ ምንድን ነው?
- ለመጀመሪያ ጊዜ ስለ ቤት ለቤት እንክብካቤ ያወቅሽው እንዴት ነው? ማን ነገረሽ? የሰማሽው ምን ነበር?

2. **የጠበከውን አገኘህ(በበጎ ፈቃድ ስራህ ረክተሀል)**

- አገልግሎት መስጠት ስትጀምሪ ምን ጠብቀሽ ነበር? የጠበከሽውን አግኝተሻል?
- አሁን ስለ እንክብካቤው ምን ይሰማሻል? እንዲህ እንዲሰማሽ ያደረገው ምንድን ነው?
- የእንክብካቤውን አገልግሎት መቀጠል ትፈልጊያለሽ? ለምን?
- የእንክብካቤ ስራውን ለማቋረጥ አስበሽ ታውቃለሽ ?

3. **ሌሎች ሰዎች የቤት ለቤት እንክብካቤ ስራን እንዲሰሩ ታበረታታለህ**

- ሌሎች ሰዎች የቤት ለቤት እንክብካቤ ስራን እንዲሰሩ ታበረታታለሽ?
- ሰዎች ከቤት ለቤት አገልግሎት የሚያቋርጡት ለምንድን ይመስልሻል?
- ስለ ቤት ለቤት እንክብካቤው አገልግሎት ቀጣይነት ምን ታስባለሽ? በተለይም በበጎ ፈቃደኞች የሚሰራውን?

4. **በጎ ፈቃደኛ ተንከባካቢዎች ቀጣይነት ያለው አገልግሎት ለመስጠት ያለባቸው ችግር ምንድነው?**

5. **ምንመሻሻልአለበት?**

Annex 7. In-depth interview guide for community workers

- What do you think motivates volunteers?
- Have you ever done a volunteer work? What kind? What motivated you?
- What do you think volunteers benefit from being a caregiver?
- What do you think people drop out? What reasons do they have to drop out?
- What do you think about sustainability of HBC program?
- What are the challenges of caregivers?
- What should be done?

Annex 8. In-depth interview guide for community workers (Amharic)

የቃለ መጠይቅ መመሪያ

- በጎ ፈቃደኞች ይህን ስራ እንዲሰሩ የሚያነሳሳቸው ምንድን ነው ብለው ያስባሉ?
- የበጎ ፈቃድ ስራ ሰርተው ያውቃሉ? ምን አይነት? ምን አነሳሳዎት ?
- በጎ ፈቃደኞች የቤት ለቤት እንክብካቤ በማድረጋቸው የሚያገኙት ጥቅም ምንድን ነው ብለው ያስባሉ?
- ሰዎች ከዚህ ስራ ለምን የሚያቋርጡ ይመስላችኋል? ምን አይነት ምክንያት ነው ያላቸው?
- ስለ ቤት ለቤት እንክብካቤ አገልግሎት ቀጣይነት ምን ያስባሉ ?
- ተንከባካቢዎች የሚያጋጥሟቸው ችግሮች ወይም እንቅፋቶች ምን ይመስላችኃል?
- ምን መደረግ አለበት ብለው ያስባሉ?

Annex 9. FGD guide for volunteer caregivers

1. What motivates you?

- What motivated you to become a care giver? Why did you become a volunteer care giver?
- How do you describe volunteering? What is volunteering?
- How did you first find out about HBC? Who told you? And what was the information you heard?

2. Have you achieved your expectation(are you satisfied with your work as volunteer)

- What was your expectation when you start giving the service? Did you get your expectations?
- What do you feel about the care giving now? What makes you feel that way?
- Do you want to continue providing care for PLWHAs? Why?
- Have you ever thought about quitting the care giving?

3. Do you encourage others to volunteer

- Do you encourage people to become volunteer care givers?
- Why do people drop out from HBC programs?
- What do you think about the sustainability of this home based care programs by volunteers?

4. What are the challenges in care giving

5. **What need to be improved**

Annex 10. FGD guide for volunteer caregivers (Amharic)

የግሩፕ ውይይት መመሪያ (ለበጎ ፈቃደኞች)

1. ምን አነሳሳሽ

- ተንከባካቢ ለመሆን ምን አነሳሳሽ? ለምንድን ነው ተንከባካቢ የሆንሽው?
- በጎ ፈቃደኛነትን እንዴት ትገልጪዋለሽ? በጎ ፈቃደኛ ምንድን ነው?
- ለመጀመሪያ ጊዜ ስለ ቤት ለቤት እንክብካቤ ያወቅሽው እንዴት ነው? ማን ነገረሽ? የሰማሽው ምን ነበር?

2. የጠበክውን አገኘህ(በበጎ ፈቃድ ስራህ ረክተሀል)

- አገልግሎት መስጠት ስትጀምሪ ምን ጠብቀሽ ነበር? የጠበከሽውን አግኝተሻል?
- አሁን ስለ እንክብካቤው ምን ይሰማሻል? እንዲህ እንዲሰማሽ ያደረገው ምንድን ነው?
- የእንክብካቤውን አገልግሎት መቀጠል ትፈልጊያለሽ? ለምን?
- የእንክብካቤ ስራውን ለማቋረጥ አስበሽ ታውቃለሽ ?

3. ሌሎች ሰዎች የቤት ለቤት እንክብካቤ ስራን እንዲሰሩ ታበረታታለሼ

- ሌሎች ሰዎች የቤት ለቤት እንክብካቤ ስራን እንዲሰሩ ታበረታታለሽ?
- ሰዎች ከቤት ለቤት አገልግሎት የሚያቋርጡት ለምንድን ይመስልሻል?
- ስለ ቤት ለቤት እንክብካቤው አገልግሎት ቀጣይነት ምን ታስባለሽ? በተለይም በበጎ ፈቃደኞች የሚሰራውን?

4. በጎ ፈቃደኛ ተንከባካቢዎች ቀጣይነት ያለው አገልግሎት ለመስጠት ያለባቸው ችግር ምንድነው?

5. ምን መሻሻል አለበት ?

Annex 11. FGD guide for nurse supervisors and community workers

1. **What motivates people to volunteer**
   - Why do people become volunteer care givers?
   - What kinds of benefits do people get from care giving?
   - How is the willingness of volunteers to give long term service?

2. **What are the challenges of care giving?**
   - What do you think about the sustainability of HBC program?

3. **What need to be improved?**

Annex 12. FGD guide for nurse supervisors and community workers (Amharic)

የግሩፕ ውይይት መመሪያ (ለነርሶች እና ህብረተሰብ ሰራተኞች)

1. **ሰዎችን ተንከባካቢ ለመሆን ምን ያነሳሳቸዋል**

   - ሰዎች ለምንድን ነው በጎ ፈቃደኛ ተንከባካቢ የሚሆኑት?
   - ከተንከባካቢነት ሰዎች ምን አይነት ጥቅም ያገኛሉ?
   - በተንከባካቢነት ለመቀጠል ያላቸው ፍላጎት አንደት ነዉ?

2. **የተንከባካቢነት ችግሮች ወይም እንቅፋቶች ምንድን ናቸው?**

   ስለ ቤት ለቤት አንክብከቤ ቀጣይነት ምን ተስባላችሁ?

3. **ምን መሻሻል አለበት ?**

Annex 13. Registration form for FGD and in-depth interviews

FGD/Interview Identification Code: _____ Date: _____

Full Name of the Participant: _____

Sex: _____

Age: _____

Marital Status: _____

Educational Status: _____

Occupation: _____

Category: _____

Annex 14. FGD/in-depth interview recording sheet

Title of the study: to describe the motivation of volunteer home-based care givers of PLWHA in Addis Ababa.

FGD/interview identification code: _____ Date: _____

Type and number of participants: _____ Location: _____

Moderator: _____ Note taker: _____

Time started: _____ Time ended: _____